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ABSTRACT

The paper's focus is primarily on services to help rural mothers of handicapped children move from a point of bare survival to a more fulfilling life. These needs are explored: overcoming feelings of isolation; developing a support system through connection to formal and informal resources within the mother's geographic area; arranging opportunities for experiences with other handicapped children and their parents; and exploring alternatives to facilitate personal growth and fulfillment. Case illustrations are included. The dual isolation of geography and being the parent of a child that is "different" is emphasized throughout. The current political climate of shrinking rather than emerging resources is considered in recommending helping strategies through expansion of the roles of existing agencies and professionals to more adequately meet identified needs. (Author/BRR)

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Unique Needs of Rural Mothers of Handicapped Children

This paper explores the following needs of rural mothers of handicapped children: (1) Overcoming feelings of isolation; (2) Developing a support system through connection to formal and informal resources within her geographic area; (3) Arranging opportunities for experiences with other handicapped children and their parents and (4) Exploring alternatives to facilitate personal growth and fulfillment. Case illustrations are included. The current political climate of shrinking rather than emerging resources is considered in recommending helping strategies. The focus is on expansion of the roles of existing agencies and professionals to more adequately meet identified needs.

Unique Needs of Rural Mothers of Handicapped Children

Introduction:

Existing literature dealing with parental reactions to a handicapped child does not typically address the unique problems experienced by rural parents faced with this responsibility. Helping strategies recommended frequently require intensive counseling services and specialized treatment programs which are not accessible to rural families.[1] The impact of a handicapped child on both parents and the total family unit is fully recognized. However, the focus of this paper is on the needs of the rural mother who, in spite of changes in the role of women in society today, retains the major responsibility of caring for the handicapped child. This pattern is felt to be more prevalent in rural areas where traditional roles are relinquished more slowly and opportunities for gainful employment are more limited than in urban areas. The options available to the mother of a handicapped child are further reduced due to the difficulty of arranging for appropriate child care should she need or desire to work.

In 1911, the Commission on Country Life noted that "whatever general hardships such as poverty, isolation . . . may exist on any given farm, the burden of these hardships falls more heavily on the farmer's wife than on the farmer himself. In general, her life is more monotonous and more isolated, no matter what the wealth or the poverty of the family may be." [2]

Certainly life for rural women has changed in these past 70 years in many of the same directions as the role of women in society at large has changed. [3] Nevertheless, isolation remains a part of life in rural homes, particularly those in which a handicapped child is a part of the family.

In reporting a survey conducted in 1973 of families having a developmentally disabled child in three largely rural counties in Alabama, William Dunlap found that the handicapped person had most negatively affected the family in activities which would take family members outside the home. [4] Specifically, "trips, . . . visiting, shopping,

going to movies or to church, whether the mother should work, where the family should live, or the effect on the head of the household's job" [5] were mentioned as areas of life most affected. His findings also showed that money problems, caring for the child, and the physical demands of time were seen as major problems by these families. [6] In reviewing the problems cited, the demands of time and child care fall most heavily on the mother who may feel that she is virtually alone in her plight.

I. Overcoming Feelings of Isolation:

In rural areas, resources for the handicapped and their families are extremely limited. Transportation expense and travel time, necessitating lengthy absences from work which the family can ill afford, are realistic obstacles. In addition, parents may feel that transporting the child is more burdensome and tiring for themselves and for the child than remaining in the home without services. [7]

Thus, the mother may find herself struggling to meet daily demands with little or no support. Parents frequently report that "by the very act of having a handicapped child, they seem to be cut off from the normal stream of things that would sustain them." [8] Certainly this is true of rural mothers whose neighbors frequently have had little exposure to children who are retarded or handicapped in other ways. Their lack of knowledge and understanding may contribute to uncertainty and unfounded fears which stand in the way of the spontaneous interaction which would normally occur.

The mother of a handicapped child is further isolated from her peers with the realization that her child is different. The disability will always be, to some extent, a separating factor. The child may never be able to meet the expectations of the parents or the community either as a developing child or in achieving the goal of self-sufficiency as an adult. His failure to do so may be interpreted by the mother as failure on her part, and she may feel guilty, disappointed, and inadequate. [10] These feelings may be experienced more deeply by the mother than the father since, as a woman, she physically "produced" the child. [11] The trauma is even greater in a marital relationship in which

the husband blames his wife for the child's disability, and she fears the repercussions of having disappointed him. [12]

The rural mother is likely to be particularly vulnerable in this regard due to the traditional emphasis on her contribution in reproduction and child rearing and the continued importance of this role. In fact, the current trend away from farm families working together as a unit has actually shifted almost total responsibility to the woman as more rural men now work away from the home in non-farm occupations. As maternal responsibility has increased, so has "potential culpability if something goes awry in the process." [13]

Evidence of this attitude is found in the desperation of a rural mother who brought her 13 month old child to an evaluation center fifty miles from her home "to find out why she's so much slower than my other children were." She told the therapist that her husband had warned her that, "if this child is retarded, it's your fault." Her determination to help her daughter "catch up" was so great that she travelled the one hundred mile round trip to the Center weekly, with very few absences, to obtain speech and physical therapy and infant stimulation for more than a year. This effort required considerable sacrifice as she was a working mother in a family of five with total income of $11,500. Although the child made gains, particularly in gross motor skills, her lack of progress in language and cognitive areas necessitated a staff recommendation for full-time placement in a developmental day care program. The mother was distraught as her consistent efforts to help her child had fallen short of her goal. In addition to the emotional trauma of accepting the need for such a placement, the geographic barriers posed practical problems as the day care center was approximately twenty-five miles from her home. Several months were required to work through the practical and psychological problems surrounding placement. Transportation was finally arranged by grouping for travel three children within a ten mile radius who needed day care services.

Thus, the isolation experienced by rural mothers is both spatial and emotional.

The ongoing anxiety, frustration, and disappointment as well as increased physical and financial demands heavily tax the mother's coping capacities. In High Risk Parenting, Catherine Cropley speaks to the heightened possibility of child abuse and failure to thrive when a mother is faced with the responsibility of caring for a high risk child. [14] Obviously, the type of handicap, the degree of impairment, whether or not it can be seen and whether or not it can be corrected are factors which influence the emotional responses of the parent and the child and produce difficulties of varying degrees. [15]

In carrying out our legal and ethical responsibilities to meet the needs of the handicapped child, we may overlook these parental difficulties and operate under the illusion that the mother is willing and able to provide constant care and to carry out home treatment programs designed to facilitate the child's development. In actuality, the mother's own unmet needs, demands upon her time from other children and home responsibilities, and the limited environmental resources available to her may make it virtually impossible for her to work extensively with her handicapped child. Consequently, she is likely to agree with the professional when asked to carry out specific activities in the home and then find that she simply is not able to follow through. The burden of her guilt is thereby increased, the child is not helped, and the professional sees the mother as uncooperative. To lessen the likelihood of this unhappy outcome, the professional has a responsibility to consider the individual needs and capabilities of the mother at a given time. Obviously, the degree to which physical and emotional stress is experienced varies with each mother and with any mother from one point in time to another. A means of acting on our concern for the mother is to explore with her the current stresses with which she is dealing, the degree to which her functioning as a mother and as an individual is affected, and the degree of isolation she is feeling. The professional's role then becomes one of helping her to identify potential sources of support, whether formal or informal, within her geographic area.

II. Developing Support Systems:

Rural areas are traditionally known as settings where "everyone knows everyone else," [16] extended families live in close proximity, and neighbors help each other. Yet the physical presence of family and neighbors is not necessarily an asset. Consider the following client comments:

"I can't take Joe to see his grandparents anymore. They told me he's too bad. They can't stand to have him around," or "My neighbor used to keep Ann for me sometimes, but now that she's getting so heavy and still isn't walking, she says it hurts her back to lift her so she can't keep her any more."

On the opposite end of the spectrum are the grandparents who cannot accept their grandson's handicap saying, "There's nothing wrong with him. He looks just like his father," or the overprotective grandparents of the CP child who were accustomed to telling her nineteen year old parents what to do. They hid the child's walker in complete confidence that their actions were in the best interest of their granddaughter and insisted that the parents were risking harming her by following the recommendations of the physical therapist in helping her learn to walk.

The social worker needs to be aware of the nature of the relationships between the mother and significant others and to help her deal appropriately with existing conflicts. Grandparents or other relatives who are closely involved with the child's care should be included in interpretive and planning conferences whenever possible. Efforts should be made to connect the mother to at least one supportive person. The local church, school, health department, and community service clubs are possible sources of help. [17] The contact person may be someone without formal training who is willing to give of herself and of her time. What is needed is an individual with whom the mother can have frequent contact and with whom she can feel comfortable. Often a teacher or a nurse fills this void as the mother builds a relationship with her in the course of obtaining services for her child.

In some rural areas, the transportation barrier has been addressed through the

introduction of mobile units and commuting professionals to bring services into the home.[18] In these home-based programs, periodic consultation with traveling trainers is provided, but emphasis is placed on the parent's role as principal teacher of the child.[19] These programs [as described by Hutinger and McKee in "The Baby Buggy" and in a National Rural Project publication, Parent Involvement in Service Delivery], stress the importance of attention to the emotional and ego needs of the parents.[20] The function of the worker appropriately includes the giving of guidance and support to the parent.[21]

Obviously these services are not available in every area. The formal resources which are available vary greatly from one community to another making it impossible to identify specific agencies which may be of help universally. However, basic public services must often expand their functions to provide services to the handicapped not offered by that particular agency in urban centers.[22] Thus, parents frequently have difficulty in locating appropriate services. A lack of direction in this endeavor was noted by 2/3 of the families of handicapped young persons participating in a study reported in 1977 and was the single problem most frequently mentioned.[23] This study was conducted in areas of diversity in size, population, and extent of urbanization in the states of California, Massachusetts, and Wyoming. Handicapping conditions were of four types: totally blind, partially sighted, profoundly deaf, and hard of hearing.[24] In regard to bringing some sense of order to the confusion resulting from the absence of a central source of information, one parent expressed the feeling, "Someone should do it!"[25] Indeed someone should, and a social worker functioning in the role of broker in linking people with resources seems to be the appropriate someone! Compiling comprehensive up-to-date data on resources for varied handicapping conditions to be shared with parents could reduce frustration and facilitate early participation in service programs.

The case coordination system serving persons with developmental disabilities, is an example of a national effort to provide a single point of access to services.[26]

This program, created in 1979 and currently implemented on a statewide basis in South Carolina and regionally in most other states, provides for the assignment of a case manager who provides lifelong services to the developmentally disabled person and his family, one of which is the location of resources. [27] Thus, the need for a central information and referral service is being addressed for this particular group of disabled persons.

Regardless of the type of disability, the crucial issue for the professional having the initial contact with the family is to provide assistance in making a connection with a helpful agency, organization or individual.

III. Arranging Opportunities for Experiences with Other Handicapped Children and Their Parents:

A major source of support for parents of handicapped children is other parents with children having similar handicaps. Groups are often formed offering an opportunity for these parents to share common feelings, experiences, and concerns and to gain support from each other. [29] Friendships, particularly among mothers, may be formed and telephone calls, visits, and child care exchanges may provide mutual help of an ongoing nature. Such experiences are difficult to arrange in rural areas due to the transportation problems of bringing parents together in a central location.

Still the need to know others like themselves is strongly felt as the following case illustrates: A social worker visited the home of a six year old child believed to be autistic. The purpose of the visit was to obtain a social history and to observe the child in his home and school environment prior to his coming to a Diagnostic and Evaluation Center sixty miles from his home. The mother was at home with this child and a younger sibling. She had no telephone and no car during the day. The child was observed repeatedly hitting and pinching his mother, making high pitched sounds, and jumping up and down screaming. He had not attended school from mid-December until the week of February 2 as the school could not manage his behavior and began calling the mother to come and take him home during the day. Transportation problems prohibited

her doing this so she removed him from school. He had returned to school during the week of this visit for a partial day at which time one-to-one instruction and transportation were being provided by the school.

The mother reported that she rarely went anywhere because "people ask so many questions about the way Bob acts." She said he had been "tested before." She had received suggestions for working with him at home but she said she did not understand what she had been asked to do and had not followed through with the home treatment program.

This mother's questions of the interviewer indicated the depth of her anxiety as she asked, "Have you ever seen a child like mine?" "Are they ever helped?" "What happens if you can't do anything?" She expressed the feeling that she would like to see another child like Rob since she and her husband had "never seen one like him."

Acting on this mother's need, the social worker arranged for her to observe the autistic class in progress at the Center during Bob's evaluation. The mother noted one child in particular who reminded her of Bob and was thrilled to see her sitting at a table participating in an activity. The teacher shared with the mother some of the progress the children had made. The mother was greatly encouraged from this observation and expressed the wish that Bob could come to this program.

The evaluation results revealed that Bob did indeed need placement in an all day program for autistic children which was not available in his school district. In this situation, a school-based program was written for his teachers to be utilized in the self-contained EH class in which he was placed. A possibility existed that one of his teachers would obtain training in teaching autistic children during the summer.

Although Bob's needs could not fully be met, his mother's need to know that she was not totally alone in having an autistic child was met. Thus, arranging for mothers to observe other children similar to their own and, when possible, helping them to meet other mothers of handicapped children may help to alleviate feelings of aloneness. Deliberate efforts to bring this about are particularly important for mothers in rural

areas who are not likely to have these contacts naturally.

The National Rural Project, while strongly recommending community individualization in problem solving, has identified from research five needs as "potentially generic to rural areas." [30] One of these is the need for improved parent involvement. [31] The suggested strategy for meeting this need is the formulation of parent coalitions with a focus on parent training and advocacy. These coalitions are seen as helpful to parents and their handicapped children. [32] Although the difficulty of organizing groups of rural parents has been cited, efforts to do so should not be abandoned.

IV. Exploration of Alternatives:

In spite of the dual limitations experienced by mothers as a result of living in a rural area and having a handicapped child, we need not be overwhelmed by what is missing to the extent that we fail to recognize possibilities for growth. We must keep in mind that the parents of children who are disabled are people first and as such are "only human." [33] As is the case with each of us, each parent must identify her own individual needs and assume responsibility for her own growth. To do so involves taking risks and being willing to try something different as is true universally in the growth process. [34]

These ideals may seem out of reach in the face of the realities of the day-to-day existence of rural mothers who have little time or motivation to seriously consider changing their lives to increase personal growth and fulfillment. Yet the social worker can help the mother to move in this direction through working with her in identifying goals, both short-term and long-term, and in realistically evaluating alternatives for reaching these goals. A short-term goal might be as simple as arranging for the father to handle home responsibilities one night a month to enable the mother to attend her church circle. A long-term goal might be taking courses in a technical school to develop marketable skills. As in other areas of social work practice, it is important to set goals which can be attained to prevent the onset or regression to a "what's the use" syndrome.

A positive attitude on the part of the professional conveying confidence in the mother is needed. Although the capacity for growth of each parent varies and, at times seems nonexistent, we must retain our faith in the potential for growth in every human being, including mothers! The degree to which the parent progresses is dependent on his inner and outer resources and the degree to which the professional provides support and challenge. [35]

Conscious effort is required to provide this focus on the mother in whatever contacts professionals may have with her since rural mothers are not likely to directly seek help for themselves. For the most part, the rural mother seeks outside assistance only in relation to the concrete needs of her child or her family. She does not typically request or receive counseling services to help her with her feelings concerning her handicapped child. On the contrary, the Dunlap survey referred to earlier reported that counseling was not mentioned at all as a service received or felt to be needed by the rural families in the sample population. [36] Needs cited most frequently were for services which would make the child more independent and better able to care for himself; specifically, financial, medical, and educational services. [37] This survey concluded that priority should be given to making these concrete services readily accessible to rural families for the benefit of the child and the parents. [38] The deduction could be drawn that services to increase the child's independence would, in turn, give the mother increased freedom to pursue her own interests.

This need for emphasis on concrete services is supported in Ginsberg's book in the statement that "services related to sustaining life will have priority . . . over social services focused on the quality of life." [39] Yet, in providing these essential services, is it not possible that we may, in the process, also help to improve the quality of life?

Conclusion:

In the present political climate, we can expect shrinking rather than emerging resources. Therefore, any efforts to increase help to rural mothers must come through creative use of existing agencies and personnel. Since the needs and resources of rural communities vary greatly, specific plans should be tailored to the area to be served.[40]

No solutions to the complex needs which have been identified can be offered. However, a point of departure could be the creation of a team of professionals and residents who agree to work together in providing services to the handicapped. These individuals, of different professions and personal interests, could then pool their knowledge and efforts to identify local needs and develop strategies to move in the direction of meeting these needs. A social worker in the area would seem a logical choice to take on the task of bringing together committed persons. A large group is not needed - what is needed is concern for the handicapped and their families; a cooperative spirit in collaborating with other members of the team, and a willingness to seek innovative means of providing services. The social worker in rural areas is typically deprived of opportunities to work as a member of a team.[41] However, the field of services to the handicapped is one in which a team approach is widely recognized as essential to meeting the diverse needs of this particular client group.[42] The concept of a community team, while limited by the interests and skills of persons available and willing to serve, is seen as a means of helping to meet both professional and client needs.

In this discussion of the needs of rural mothers of handicapped children, the focus has been primarily on services to help these mothers move from a point of bare survival to a more fulfilling life. In general, the suggestions offered call for an expansion of our present roles to the point that we are more attuned to the unique needs of mothers as we continue our work with handicapped children and families. The benefits of any successful efforts to meet these needs will be realized not only by the mother but by the total family unit. By the same token, we cannot expect the child to reach his

fullest potential without the positive involvement of the mother. Thus, the area of service to rural mothers, fathers, and siblings of handicapped children is seen as one in which further study and effort is needed.

Notes

1. See, for example, Helen Beck, "Counseling Parents of Retarded Children, Children, 6 (November - December, 1959, pp. 225-230; Simon Olshansky, "Chronic Sorrow: A Response to Having a Mentally Defective Child," Social Casework 43 (April, 1962), pp. 190-193 and Milton Seligman, Strategies for Helping Parents of Exceptional Children (New York: Macmillan, 1979), pp. 114-184.

2. Thomas R. Ford, "Rural America: Persistence and Change," Rural USA: Persistence and Change, ed. Thomas R. Ford (Ames, Iowa: Iowa State University Press, 1978), p. 13.

3. Ibid.

4. William R. Dunlap, "Services for Families of the Developmentally Disabled," Social Work, 21 (May, 1976), 222.

5. Ibid.

6. Ibid.

7. Patricia L. Hutinger and Nancy McKee, "The Baby Buggy: Bringing Services to Handicapped Rural Children," Rural Human Services, A Book of Readings, ed. H. Wayne Johnson: (Itasca, Illinois: F. E. Peacock Publishers Inc., 1980), p. 123.

8. "Professionals: Are You Listening?," South Carolina ARC Advocate (March - April, 1976), 2.

9. Charles R. Horejsi, "Service Delivery in Rural Areas: Context, Problems and Issues," Rural Services, ed. Jon Miller, et. al. (Chapel Hill: University of North Carolina Printing Department, 1977), p. 16.

10. Seligman, p. 46.

11. Ibid.

12. Ibid., p. 48.

13. Carnelia B. Flora and Sue Johnson, "Discarding the Distaff: New Roles for Rural Women," Rural USA: Persistence and Change, ed. Thomas R. Ford (Ames, Iowa: Iowa University Press, 1978), p. 172.

14. Catherine Cropley, "Assessment of Mothering Behavior," High Risk Parenting, ed. Suzanne R. Johnson (Philadelphia: Lippincott, 1979), p. 13.

15. Cheryl Hall Harris, "Assessment of Children's Behavior," High Risk Parenting, ed. Suzanne R. Johnson (Philadelphia: Lippincott, 1979), p. 54.

16. Leon H. Ginsberg, "An Overview of Social Work Education in Rural Areas," Social Work in Rural Communities: A Book of Readings, ed. Leon H. Ginsberg (New York: Council on Social Work Education, 1976), p. 6.

17. Ibid., 6-8.

18. See, for example, Susie Hubbard, "Hi-Line Home Training," Rural Services, ed. Jon Miller, et al. (Chapel Hill: University of North Carolina Printing Department, 1977), pp. 89-100; Patricia Hutinger and Nancy McKee, pp. 122-129; and "Parent Involvement in Service Delivery," Sample Abstracts, National Rural Project, Center for Innovation and Development, Murray State University, Murray, Kentucky (1980-81).

19. Hutinger, p. 124.

20. Ibid., and "Parent Involvement in Service Delivery, p. 28.

21. Ibid.

22. Ginsberg, p. 7.

23. Garry D. Brewer and James A. Kakalik, Handicapped Children: Strategies for Improving Services (New York: McGraw-Hill, 1979), p. 545.

24. Ibid., p. 547.

25. Ibid.

26. "Coordinating Services for the Developmentally Disabled Individual," (Columbia, South Carolina: South Carolina Developmental Disabilities Program, current undated pamphlet).

27. Ibid.

28. Beulah Compton and Burt Galaway, Social Work Processes (Homeward, Illinois: Dorsey Press, 1975), p. 342.

29. See, for example, Leo Buscaglia, The Disabled and Their Parents: A Counseling Challenge (Thorofare, New Jersey: Charles B. Slack, 1975) esp. pp. 195-116 and Alfred Katz, "The Role of Parent Groups in Services to Mentally Retarded," Social Work and Mental Retardation, ed. Meyer Schreibner (New York: John Day, 1970), pp. 289-292.

30. National Rural Project, "Problem-Solving Strategies" NRP Newsletter, Vol. 2 (Winter, 1981), 5.

31. Ibid.

32. Ibid.

33. Buscaglia, p. 90.

34. Ibid.

35. Jack C. Stewart, Counseling Parents of Exceptional Children (New York: MSS Educational Publishing Company, Inc. 1974), p. 81.

36. Dunlap, p. 223.

37. Ibid.

38. Ibid.

39. Southern Regional Education Board Manpower Education and Training Project Rural Task Force, "Educational Assumptions for Rural Social Work," Social Work in Rural Communities, ed. Leon H. Ginsberg (New York: Council on Social Work Education, 1976), p. 41.

40. Ted Bergeron, "Seeds of Common Sense," Rural Services, ed. Jon Miller, et al. (Chapel Hill, University of North Carolina Printing Department, 1977), pp. 117-120.

41. Horejsi, p. 23.

42. Advocacy and Service Provision to the Developmentally Disabled and Their Families, ed. David O'Hara, et al. (State of Maryland: Department of Human Resources, 1978), p. 58.